DSS Autism Spectrum Disorder Advisory Council (ASDAC) Meeting Minutes September 18, 2019

Members Present: Jennifer Abbatemarco, Jill Caron, Judy Dowd, Marcia Eckerd, Ann Gionet, Bill Halsey, Andrew Komarow, Mickey Kramer, Jim Loomis, Aileen McKenna, Jimnahs Miller, Katie Rock-Burns (representing Siobhan Morgan), Brandy Petrone, Donyale Pina, Yana Razumnaya, Lynn Ricci, Lois Rosenwald, Kari Sassu, Julie Wolf

Others Present: Kathy Bruni

Members Absent: Representative Cathy Abercrombie, Melissa Gagne, Bryan Klimkiewicz, Kathy Marchione, John Pelegano, Carole Ryan-Hanlon, Doriana Vicedomini

Call to Order: 10:05am

Welcome and Introduction by Yana Razumnaya and Bill Halsey

- Pre-meeting held prior to Council Meeting
- Welcome of new Council Members
 - o Andrew Komaro Person with Autism Spectrum Disorder (ASD)
 - Julie Wolf –Representative of an institution of higher education in the state with experience in the field of ASD

No Public Comments: Bill discussed 3 minute rule for public comments to ensure allotted time for agenda items

Review and Approval of June 12, 2019 meeting minutes

Minutes reviewed and approved

Sub-committee Committee Discussion & Reports:

- Sub-committees were established through retreat held last year
- Would like to discuss if these sub-committees are appropriate and on-target of what this Council should be doing?

Outcomes and Data: Trying to answer a simple question, though difficult to answer.

- As a result of the services that adults and children receive, are they better off? Is the level of functioning better for that individual as a result of receiving services?
- The Outcome Group is trying to think about what that means.

- Would like to establish the baseline data on level of emergency department, hospitalization, utilization, and re-admission to get this started.
- Beacon Health Options is the behavioral health administrative service organization authorizing Medicaid State Plan Services for individuals with autism under the age of 21. Providers doing this service seek authorization from Beacon Health Options and they review treatment plans and evaluations, behavioral assessments periodically. Beacon provides utilization management for adults and children receiving behavioral services. They are run data on children receiving services under the Medicaid State Plan

Jennifer Krom - Beacon Health Options presented data to Council

- Data was requested for calendar year 2016-2017. Will be working on a pre and post poll in the future and continue to pull the exact data to make comparisons year to year for successes in treatment. (Data is still in draft form, not yet available)
- The 2016-2017 poll started with children that are in service delivery, receiving services within their home setting receiving services with Beacon's Network Providers providing in-home ABA services. Service Delivery, ongoing services. Number of hours are associated with the individual treatment plan
- 2016-2017 657 individuals, actively receiving services. Of the 657, 297 individuals (45%) had an emergency room visit for behavioral health reasons. Of the 297, 164 individuals (25%) had another emergency room visit within 30 days. 25 (16%) of the 297 had a readmission within 7 days of being discharged from the emergency room
- Beacon also pulled information on inpatient psychiatric admissions. Of the 657, 87
 had an inpatient admission for behavioral health reasons while actively receiving
 services. Of the 87, 42 once discharged were readmitted within 30 days. Of the 42,
 10 were readmitted within 7 days.
- Took a look at the 10 individuals that were readmitted within 7 days. Took a look at the authorizations and across the board they have used all available services
- Options/Protocols available to families and individuals in crisis/complex situations include peer specialists which help build resources. Recommendations would first have to come from clinician working with the individual
- It is commons that many of these individuals have aggressive behaviors and the appropriate discharge is very important. The discharge procedure for individuals that are too violent to live at home can be challenging and many are held at the inpatient unit because it's difficult to come up with the appropriate and safe discharge plan. Some options may include an intensive in-home team coupled with intensive outpatient therapy and at times some parents still are uncomfortable with

- the discharge plan which delays the discharge and at times the parent refuses the child to come home.
- Partnership between Beacon and other agencies to provide different supports is very beneficial at times like these. Being creative and creative wrap services can be helpful different funding sources and different service providers in order to meet the needs of the individual and family.
- Inpatient stay Inpatient facilities including IOL Institute of Living, Yale, general psychiatric inpatient settings.
- Information needed from Council so that Beacon can gather more detailed data
- Beacon is focusing study on the 10 Individuals Profile of 10 individuals
 - ASD is one of the many diagnoses
 - o Significant psychiatric diagnosis, which is often primary
- Useful Data Items/ Questions to Explore:
 - o Gaps in treatment?
 - Comparing data against HSC would be interesting. Lynn Ricci will be reporting on HSC's data
 - Are services provided proactively or during crisis? Jennifer Krom advised that their goal is to be proactive?
 - o Rate of hospitalization before home-based services?
 - o How do we know service is working?
 - Common treatment intervention plan?
 - o Homelessness? Economic status, ability to access services can be difficult.
 - o Is treatment being offered not fitting families' needs?
 - o Culture?
 - Complex family dynamics?
- Beacon is working with Intensive Response Team and building relationships with Connecticut Children's Emergency Department and Yale to try to be preventative in work they are doing. These facilities are sharing with Beacon individuals who they have tried to reach out to sometimes without success to coordinate care and link them to services. It isn't until the family is ready as this can be overwhelming as it is intensive and invasive to have someone in your home for the amount of time required.

Creating Hubs and Centers of Excellence: (Jimnahs Miller)

 Subcommittee was formed out of a vote from the retreat with the specific goal to improve connections and resources for individuals and families with autism across the lifespan finding housing, meaningful career, healthcare and additional services.
 Work plan draft including providers, eligibility, coverage, advocacy, education, financial, housing, career, social.

- Presented models from different states at the retreat
- Published updates on work plan leveraging existing resources
- Resources including ASRC, list of Connecticut licensed providers, Medicaid provider list and Infoline 211
- Updates on work plan
- Goal to publish list on 211website
- Reaching out to parents and organizations and creating "problem statements"
- Goal is to offer list of resources to different populations
- Mirroring different models for delivery that we see in other states, particularly Missouri
- Utilizing a university school system, statewide agency or organization where we can identify providers within the region and link together
- Covering different areas in Connecticut in need
- Yana offered to provide information on self-advocacy groups within the state through DDS
- Requested suggestion from the Council for other ideas
- Suggestion to add support groups for families and adults
- Suggestions for HUBS
- What is the training and outcomes?
- Suggestion for center or dedicated space used for activities and socialization

Training: (Kari Sassu) Longstanding that individuals who provide services to adults and children with autism would benefit from additional specialized ongoing training

- Goal of subcommittee is to enhance or improve training which school personnel, clinicians and families receive.
- New Members include Bryan Klimkiewicz and Julie Wolf
- Recruiting additional members to join committee
- Discussion of creating a bridge, collaborating with the Centers of Excellence subcommittee or creating HUBs. Will discuss with Jimnahs.
- Bill suggested that sub-committees have a conference call for more detailed discussion of teaming up
- Importance of First Responders receiving training so that they can better understand the autism population and how to handle safely and appropriately
- Bus drivers can benefit from training
- Jennifer Krom advised that Beacon provides training at the Police Academy
- Jennifer Krom pairs up with, DDS, DMHAS, and DCF Speech Pathologist and trains mobile crisis technicians across the state and trainings provided at the State Police Academy

- CHCI pairing up with Beacon
- ASRC also provides training at the State Police Academy
- DMV is working with ASRC identifiers for drivers
- Discussion of making this a Legislative priority as far as funding for police departments to provide training
- Unfunded mandate for First Responders at this time
- Suggestion for different organizations to put together list of trainings and supports being offered
- Suggestion for Director of Autism for coordinating
- Suggestion for individualized crisis intervention plan, identifiers
- Importance of consistency throughout the state, possibly a HUB

ASD Feasibility Funding

- Ongoing updates will be provided at ASDAC meetings
- State Plan updates
- Lifespan Waiver updates
- Beacon Intensive Response Team presented by Jennifer Krom
 - State funded for initiatives
 - Started accepting referrals on June 3, 2019
 - Vision is to enhance the system of care for members and families impacted Autism Spectrum Disorder, Intellectual Disability and Developmental Disorders
 - Goals to decreased emergency room visits, inpatient psychiatric hospitalizations and psychiatric residential treatment facility utilization and length of stay
 - Increase the referral and connection to increase appropriate levels of care, support and services. At the end of pilot year, summary will be put together with BEST practices to recommend through program that they find through the data
 - Referral criteria for program is for any individual who has been diagnosed with ASD, Intellectual Disability or Developmental Disability, individuals at risk of overstay in the emergency department of discharge from inpatient setting, can be up to 26 years of age regardless of funding source. May have utilized multiple services or hospitalizations that were unable to meet their needs, present either the Connecticut Children's Emergency Room or Yale New Haven Children's or their main hospital.
 - Worked closely with Connecticut Center for Care Coordination and Emergency Department Social Workers. Individuals have the opportunity to

- engage with coordination with the Care Coordinators and accessing resources
- Beacon's Care Coordinator visits Connecticut Children's Hospital twice per week after rounds for individuals who may have need in the moment of crisis
- o Families are highly complex, including mental health, housing issues
- Connecticut Children's (serve individuals primarily ages 6-13)
 - O 37 referrals from the Emergency Department and Center for Care Coordination. 21 were deemed appropriate for the Intensive Response Team as they have met the criteria. 2 have been successful discharges. 4 have been closed for various reasons. 2 were unable to contact. 1, there was no family identified to work with. (DCF custody) 13 individuals were referred to the ASD based team, State Plan Services, still accessing support and services. 2 went to the Intensive Care Coordination Teams due to a primary psych diagnosis and needs. 2 were closed due to being placed into a group home from emergency department. Of the 37 referrals 3 were commercially insured
- Yale utilization (serve individuals primarily ages 18-23)
 - O 14 referrals from Yale facilities. 9 have stayed with the Intensive Response Team. 1 successful discharge. 6 were closed due to various reasons. 2 were unable to contact. 1 was an inappropriate referral made through the Yale ICAPs Team. 1 was referred to CHN (medical ASO) due to medical complexities but will be teaming up with them for autism specific resources. 3 went to the ASD based team and were assigned a Care Coordinator. 2 were assigned to the Intensive Care Coordination Team. 4 were commercially insured.
- There is a high need for providers
- Hospital for Special Care update will be presented at the November 20, 2019 ASDAC meeting
- ASRC will present at 2020 meeting
- Center for Children with Special Needs
- Suffield Public School

Discussion:

- ASD Feasibility Dollars for next year
- Discussed the idea of combining **Training** and **Centers of Excellence**
- Suggestion for October meeting with possible locations Hospital for Special Care or Beacon Health Options

ASD Waiver Update by Kathy Bruni:

• Number served: 110

• Participants enrolled in 2019: 6

• Number in transition process: 4

• Participants that left the waiver in 2019: 1

• Number on Waitlist: 1566

Future Funding Projects and Legislative Session

 Suggested October meeting to discuss where to invest state dollars and legislative priorities

- Suggestion to use state dollars
- Vocational program

Other Business:

- Brandy Petrone passed out Disability Rights of Connecticut handouts
- Ann Gionet suggested getting up-to-date data on the state of Missouri numbers for setting up a center

To Do:

- Bill to send out proposed dates for October meeting
- Bill to touch base with Cathy Abercrombie
- Beans and Co. recommended by Yana (staff includes individuals with ASD)

Adjournment: 11:58am

Next Meeting: Wednesday, November 20, 2019 at 10:00am

Legislative Office Building Room 2A